

## Action research to improve the human condition: An insider-outsider and a multi-methodology design for actionable knowledge outcomes

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# **Action research to improve the human condition: An insider-outsider and a multi-methodology design for actionable knowledge outcomes<sup>\*</sup>**

Margaret Vickers

The purpose of this manuscript is to share the development of an action research project that utilized different methodological perspectives for different stages of the project. I begin with a brief overview of the substantive orientations of the project, before concentrating on the particulars of the research process. I focus on, to start, my status as a researcher "insider-outsider" to both the research process and investigated phenomenon. A detailed explication of the action research design follows, drawing attention to the three distinct evolving stages of the project, and my use of both Heideggerian phenomenology and naturalistic inquiry to elicit the rich data required for this action research project. Data is presented from each of the three stages of the study to demonstrate how the generation of actionable knowledge took place. The journey from learning and the creation of local theory, to an action plan and practical, actionable knowledge outcomes is carefully explored. The paper concludes by sharing how actionable knowledge outcomes at the local, individual level can also be used as input to actionable knowledge on a much wider scale with a national study, currently underway in Australia being described – all in the interests of improving the human condition.

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**Keywords:** Action research, qualitative research, narratives, careers, chronic illness

### **A research project to improve the human condition**

It has been suggested that social scientists carry a special burden of responsibility. It is necessary but not enough that the profession engage in disinterested pursuit of knowledge. It must encourage and support within itself scientific work that has as its aim the mutual enrichment of social sciences and the practical affairs of man [sic]. (Emery 1977, 206).

The purpose of this manuscript is to report on an action research project and show how the evolving nature of the project contributed significantly to what action research ultimately seeks to do – to improve the human condition. Action research exists to promote liberating social change (Greenwood 2002, 128). Like the study conducted by Emery and Thorsrud (1975, 1), the first stage of this project concentrated on the experiences of participants, while the latter stages focused more on opportunities for human development and social change. Like Emery (1977, 1), I was seeking to identify ways in which examining and changing the conditions for participants could assist in making their future. I have included data in this manuscript, not to demonstrate particular substantive themes or outcomes from the research per se, as is usually the case with qualitative research reports. Instead, I report the development of one theme to depict the development of the various stages of the research process, and how each succeeded in capturing relevant and meaningful data, how the data gathered was influenced by the researcher's choices, how the process positively influenced respondent's lives and, ultimately, how the project has mapped the path to wider social change for the future.

The action research project reported here focused on the lives of people who work full time while also caring for a child with a significant chronic illness.<sup>1</sup> Children with chronic illness are a significant group of the population (Martin/Nisa 1996, 1). For example, in Australia where this study was insti-

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<sup>1</sup> For the purposes of this study the term "chronic illness" is intended to include any long term, significant illness or disability.

gated, of the 3.9 million children aged between 0 to 14 years in 1998, almost one in seven had a long-term health condition (594,600 or 15%), with boys more likely (18%) to be affected than girls (13%). Examples include: cerebral palsy, muscular dystrophy, asthma; cystic fibrosis; diabetes; myelodysplasia; hydrocephalus; cleft palate; burns; cancer; or other physical disability as a result of trauma or congenital anomalies (Burke et al. 1999). However, in this study, concern lay with the parents who worked full time. Several things impinged on their work lives regularly: An obvious one was the need to take children to the doctor and the existence of a chronic illness would infer an increased regularity of such visits. Also, day-to-day care for conditions such as cystic fibrosis (CF) require time consuming and stressful daily health care regimens that are rigorous and unrelenting – taxing to both children and parents. Parents report that seeing their child in physical or emotional pain is heart-wrenching, triggering overwhelming feelings of guilt and inadequacy (Melnik et al. 2001). Balancing the competing demands of such regimens while working, and maintaining personal and family responsibilities, is challenging and exhausting (Melnik et al. 2001).

Greenwood (2002, 127) confirms that action researchers delve into “messes”: complex, dynamic and difficult problems. This was certainly one of those. Living with chronic conditions can be very difficult for both the child involved, and for their parents and siblings (Martin and Nisa 1996). It was my contention that any difficulties would be magnified for carers needing to manage a career along with everything else. Women so placed<sup>2</sup> reported feeling different from those around them, alone in their struggles, with high levels of frustration, numerous and conflicting challenges and social roles, uncertainty and fear, as well as concerns with the pressure upon them to continue to “do it all” (Vickers/Parris/Bailey 2004). Respondents also reported a serious lack of reliable support, cruelty and thoughtlessness from family, friends, colleagues and strangers, as well as a sense of disconnection from those around them (Vickers 2005a, 2005b). These women’s struggles were notable and, yet, they apparently had little access to support.

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<sup>2</sup> Of interest, while both men and women were intended to participate in this study, only women were referred for potential inclusion. Thus, only women participated.

I begin by articulating my role in the research process. Not only was I conducting action research as a researcher who was working inside and outside the research process, I was both inside and outside the phenomenon under investigation, positions which inevitably influenced the research design and outcomes. Secondly, I describe the action research design that emerged as the project unfolded. The emergent research design embraced several philosophical methodological perspectives that interleaved comfortably, while assisting me, as the researcher, towards the essential objective – improvement of the social situation of the group of concern. Thirdly, I demonstrate the actionable knowledge (Gustavsen 2004) that has been achieved, both as practical, local changes and products of the respondents' local theory as it blossomed into local actionable knowledge, as well as more comprehensive openings for actionable knowledge on a larger scale, now underway (Palshaugen 2004a, 190).

### **An „insider-outsider”: To process *and* phenomenon**

A critical feature of action research is the involvement and input of the researcher in the process. The researcher feeds back the findings to participants along the way so that they have input on what happens next (Page/Meyer 2000, 20). Importantly, action researchers are required to be both inside and outside the research and social change process; to be engaged in it, and to reflect on the process, before, during and after action (Fricke 2004). Action research is insider-outsider and multi-party work (Greenwood 2002, 127). The main difference between action research and descriptive, empirical research has to be searched for in the difference of the *experiences incurred by the researchers* in the action research project (Palshaugen 2004a, 200; emphasis in original). The researcher must rely on their own experience from the process, whether „recorded” or not (Palshaugen 2004a, 201). Unlike many action research projects, I have not banished my personal experience, but have carefully considered it both in terms of my involvement in the process of doing the research and my proximity to the phenomenon under exploration.

In this study, I was concurrently both inside and outside the process of doing the research. I was inside the process because, as a researcher, I was con-

ducting interviews, recording field notes, making interpretations, writing and analyzing, reflecting on what I was seeing and hearing, and doing my best to respond to the research question set. However, in engaging in all of these activities I was also outside the process, to some extent. I was, from time to time, stepping back. I was considering my „separateness” from the respondents, my differing role and responsibilities, even while engaging with them during the process. I was an outsider to them; an observer, a recorder, a theorizer, and a decision maker retaining a measure of authority over what took place. I was a researcher; they lived the phenomenon under review.

Importantly, I was also both inside and outside the phenomenon under review, in several material ways. First, I was inside the phenomenon because I worked full time. I was also a woman working full time, with all the careerist and gender issues that this implied. Secondly, I had been the carer of a person (my partner) with a significant chronic illness. His condition had prompted his disability-related retirement from a banking career at the age of 43. I saw his illness rampage through our lives and witnessed, not just his physical and emotional loss and suffering, but mine. I understood the grief and loss associated with watching another’s struggle with serious illness. I had also lived the uncertainty, the changes, the inconvenience, and the fear associated with caring for another, as well as the frequent lack of understanding, consideration and support from other people. I had learned that illness and disability could undermine relationships, shift interpersonal dynamics, induce financial hardship, and initiate unending struggle, ambivalence and turmoil that the recipient is rarely prepared for. Finally, I was also a person with a significant chronic illness myself: I have multiple sclerosis. I understood the vagaries and uncertainties of chronic illness first-hand. I understood workplace discrimination; I knew the stigma, alienation, fear, loss and grief that chronic illness could bring; and I was very familiar with the unpredictable mural a life with chronic illness portrays, especially as it reaches into the future. I had coped with varying levels of disability – visible and invisible – over many years, and in concert with working and living. However, with all this, I had also learned the benefits and growth possible from surviving, the strength and fearlessness that accompanies successful encounters with adversity, and an appreciation of the joy and richness that life can bring, even when trouble

strikes. For this study, it was imperative, then, that these “inside” perspectives were enabled and acknowledged, rather than cast aside. I was, in many ways, researching from the inside (Vickers 2002).

However, in other important ways, I was on the outside the phenomenon, looking in. I have no children, so have little understanding of the mother-child bond, the selfless caring that accompanies parenthood, nor the need to juggle work and home with a child or children thrown into the time-hungry mix. I also do not have a child with a chronic illness, and profess no knowledge of the special grief and loss that this engenders, nor the particular fears for the future that parents have for a child more vulnerable than most. My concurrent proximity and distance to this research were undeniable. According to Heidegger, the researcher’s influence cannot be underestimated. Indeed, it will determine what phenomena, facts and relations will enter their consciousness (Moss and Keen 1981, 108). The researcher’s orientation, sensitivity and perceptiveness will shape the interpretations (Osborne 1990, 85; Vickers 2001). And so my journey into action research began, surprisingly, with advice from Heidegger. I embarked on the journey with the first steps only clear in my mind.

### **A multi-methodology design**

Action research projects attempt to make change, and to gather and analyse data concurrently (Punch 1998). The focus is on the applied nature of the social research, and upon taking action as a result of the findings. The desire is to effect ongoing change (Page/Meyer 2000, 20). This was an action research project that embraced, with care, several philosophical and methodological choices along the way. Action research requires the mobilization of expertise from any and all academic and research locations that are relevant, and any research methods can be relevant insofar as they have something specific to contribute (Greenwood 2002, 127).

The important connection between theory and action – social praxis – was demonstrated through the dialogues between researchers and subjects (Fricke 2004). Certainly, the respondents in this project were subjects (rather than objects) and it is hoped that, in the pages that follow, evidence of the “field talking back” will become clear (Fricke 2004). At all stages of the project, all re-

spondents were encouraged to participate (although, because of their particular circumstances, not all were able to, all the time). Certainly, I viewed the participants and myself as equal, while bowing to their vastly greater knowledge of their experiences, and choosing to retain my researcher-imbued authority over data selection, presentation and choices.

The basis of this project was the experiences of respondents (Fricke 2004), my desire to share those experiences with others (Vickers 2001), and the fact that, from the outset, this project was driven by a problem about which not enough was known: The experiences of women who worked full time and had also to care for a child with a significant chronic illness. The project commenced with a desire to learn about their experiences and moved to a process of social change, initially on a small scale involving individual participants of the study and the development of local changes for them as a result of their new knowledge, and finishing with this local theory contributing to practical steps, on a much larger scale, to work towards the introduction of much wider social change.

One of the key findings of this exploratory study revealed that these women needed much greater support than was currently available to them. The theme of “doing-it-all” is used to depict data from each stage of the project to demonstrate the knowledge that was gained of their lived experience, the learning respondents demonstrated, and the actionable knowledge outcomes that resulted. The “theory” that emerged was developed in conjunction with participants, within their social context, and was as a result of joint learning by both researcher and participants (Fricke 2004).

The creation of fruitful and mutually beneficial interaction between actionable knowledge and textual knowledge is no small task (Palshaugen 2004b, 113). The action research design detailed here consisted of several distinct stages:

**Stage 1: In-depth Interviews:** *Retrospective* Perspective; Heideggerian Phenomenology.

**Stage 2: In-depth Interviews:** *Prospective* Perspective; Clarification of Data; Responses to Vignettes; Heideggerian Phenomenology and Naturalistic Inquiry; Actionable Knowledge and Change.



**Stage 3: Culminating Group Experience:** Naturalistic Inquiry; Member Checking; Actionable Knowledge and Change.

I will discuss each Stage in detail, including the philosophical and methodological choices made, and other important influences of interest. Fricke (2004) reminds us that action researchers must be able to use a toolkit of different methods, and be especially competent in the areas of value orientation, empathy, and responsibility for the consequences of their research. I approached the field with a desire to learn, to view experiences through the eyes of my respondents, to enter into a dialogue with them, and to develop useful knowledge of the situation and contextual theory as part of a process of action and reflection (Fricke 2004). I share Dick's view that action research should be carefully considered, rigorous and high quality, while also agreeing that a single case has a useful contribution to make (Dick 2003, 256).

This study, also small scale, involved nine respondents in Stage 1; six in Stage 2; two in Stage 3. The small numbers of respondents, in my view, did not diminish the importance of these cases. The exploration made it possible for learning from experience and theory (that is, understanding from past practice) to take place (Dick 2003, 256). The project was intended to be exploratory, precisely for the reason that there was not enough information about the research subject to begin with (Sarantakos 1993, 7). The concluding remarks demonstrate my further application of the actionable knowledge gathered in these three stages in a practical way – work at social problem solving on a wider scale (Sarantakos 1993, 8).

***Stage 1: In-depth interviews: Retrospective perspective; Heideggerian phenomenology***

The study commenced by responding to this research question: *What is life like for a full time worker who also cares for a child with chronic illness?* I wanted to retain the fundamental essence of the phenomenological purpose while also developing a research design that enabled the use of multiple sources and perspectives. I had worked extensively with Heideggerian phenomenology on another project as an “insider” to the phenomenon (see Vickers 2001), so understood that Heideggerian phenomenology does not require re-

searchers to “bracket” their knowledge or experience, as would be required for either Husserlian phenomenology, or more positivistic studies. Heideggerian phenomenology enabled me to consider and value my proximity to the study at hand, vital given my insider-outsider status.

I also knew that Heideggerian phenomenology valued an acceptance of multiplicity in people’s lives and experiences, with the need to capture the subjectively experienced life of the informants as interpreted by them (Taylor 1993, 174). I wanted to know their lived experience (Oiler 1982, 178) and the meaning it held for them (Drew 1989, 431; Vickers 2001, 33). Phenomenology has been described as illuminating the richness of individual experience (Baker, Wuest and Stern 1993, 1358; Vickers 2001, 33), underscoring the importance, and value, of the informant’s reality and the need for the researcher to share that reality with others (Swanson-Kauffman 1986, 59; Vickers 2001). I remained convinced that the only legitimate source of data are those who have lived the phenomenon under investigation (Baker, Wuest and Stern 1992, 1357; Vickers 2001, 33). The value comes from learning about lived experience from the informant’s perspective – to capture experience as it is lived and share it with others – while also valuing multiple identities and multiple lives (Vickers 2001; 2005a; 2005b). In this study, the women demonstrated multiple, overlapping and conflicting lives, roles and identities. Heideggerian phenomenology allows for such a composite of realities (Oiler 1982, 179), a requirement for stories that comprised multiple voices (Gergen and Gergen 1984, 182; Gergen 1991, 83; Davis 1994, 353) and multiple lives (Bateson 1989, 162).

Interviews encouraging discussion, sharing of experiences, and *retrospective* reflections were conducted in Stage 1. Of primary concern was an understanding of the respondents’ perspective, their concerns and the meaning it held for them. Respondents were asked a series of open-ended questions focused on their experiences of caring for a child with significant chronic illness, while working full time. The questions were designed specifically to explore complex, often very personal matters (Alvesson 2003, 19).

What follows is an example of data drawn from Stage 1. Dolly lived with her intellectually disabled daughter, who suffered from severe epilepsy. Indeed, it was the epilepsy that resulted in her child’s permanent intellectual

disability. Dolly had recently separated from her husband. Dolly's mother, who had previously been living with Dolly and her husband, and providing after-school care for the child, had also just moved out after an argument with Dolly. So, Dolly was on her own caring for her disabled child and working full time. She articulated clearly her multiple and conflicting roles, her multiple identities and, as many other respondents confirmed, her experience of "doing-it-all" (Vickers, Parris and Bailey 2004):

**Dolly:** What he [Dolly's ex-partner, Steven] doesn't understand is, yes, he takes Margaret three weekends out of four. But who organises all Maggie's medication, organises all her doctor's appointments? Who takes her to all her blood tests? Who irons all her clothes? Who washes all her clothes? Who changes all her bed? Who organises all the nappies? This all just happens. Who buys all her clothes? Who finds time to go and buy her clothes and get her shoes fitted? And this all happens around Steven, and he doesn't get it. Who does all the grocery shopping? You know, the food is just there; the clothes are there. She goes with a perfect little bag, like an overnight bag, with all the medication, all the stuff. And I'm really filthy with him, because it all comes back dirty. And I said to him, you know, "You can wash. You know, it would be really good, you've got her from Friday night to Sunday night, you can wash a couple of —, you know, I don't expect two or three sets of pyjamas to come back filthy." You know, because Maggie's a bit of a grub. "You know, it wouldn't hurt you to do a wash and all that sort of thing." So, hopefully he will do that (Dolly, #1, 90).

Dolly shared her lived experience of "doing-it-all". She was reflecting on those experiences from a retrospective perspective, telling me what had happened, how she had felt and what her response was to those circumstances. As the Stage 1 interviews were guided philosophically by the tenets of Heideggerian phenomenology, I was aware that my influence as the researcher could not be underestimated. My choices determined what texts, facts and experiences were reported and my orientation, sensitivity and perceptiveness shaped the subsequent interpretations (Osborne 1990, 85; Vickers 2001a). I share my response to Dolly's text:

**Researcher Note:** *As a career woman with little time to spare myself, I understand Dolly's anger. As a chronically ill person and one who has been carer of another who I loved, the obvious lack of support Dolly is*

*experiencing is profound. I can also empathise with her efforts to manage her multiple, and often conflicting roles and identities: She was a mother, HR professional, ex-wife, carer, negotiator, and daughter; I was an academic, person with multiple sclerosis, researcher, author, wife, and daughter. How did she manage to deal with her overlapping realities and conflicting responsibilities? I know it was, and continues to be, hard for me. I remember that, at times in the past, when my partner was very sick, I felt completely overwhelmed, and wondered how I would keep going. This is just what I am hearing from Dolly. I am reminded of my responsibility to share Dolly's story (and those of the other women interviewed), to understand it as best I can, and to do something to help them and those similarly placed, if I can (Vickers, Researcher Reflections, Wednesday, 14 May 2003).*

This stage of the project centred upon the need to capture the subjectively experienced life of the informants as interpreted by them (Taylor 1993, 174). I wanted to describe Dolly's lived experience (Oiler 1982, 178) and the meaning it held for her (Drew 1989, 431; Vickers 2001a, 33). I wanted to capture the richness of Dolly's individual experiences (Baker, Wuest and Stern 1993, 1358; Vickers 2001a, 33) as she had wanted it to be known, and as she understood her reality to be. I felt that I was able to see, through Dolly's eyes, what this reality was. She thought that she had to do everything. She was angry that her ex-husband didn't see this; she was also angry that he didn't do his share. I saw Dolly's multiple roles at work and home, and the time she needed to do all these things for her daughter (especially, now, having no assistance). For me, Dolly's story illuminated her experience. Indeed, it was this passage that first highlighted the theme in my mind of "doing it all". I needed to share her experience with others; I needed to reflect this experience back to other respondents in the study to see if they felt the same way; and, I needed to get some help for these women if this was their reality.

Prior to moving to Stage 2, where I re-interviewed respondents, I reviewed the transcripts from Stage 1 for the specific purpose of developing questions from a prospective perspective. Aside from further exploring certain themes, I wanted to ask, for example: If you had your time over, what would change? What will you do differently in the future? I also took time to develop a number of fictional vignettes for presentation to respondents during that second inter-

view. Vignettes were based on literature reviewed and, importantly, from data gathered from Stage 1.

***Stage 2: In-depth interviews: Prospective perspective; clarification of data; responses to vignettes; Heideggerian phenomenology and naturalistic inquiry; actionable knowledge and change***

In many respects, the philosophical perspective of Heideggerian phenomenology also remained throughout Stage 2, especially its congruence with my role in the research process and the focus on the subjective perspective of participants. However, as I moved toward more of a learning orientation and, especially, the need to take action regarding what I was learning and what my respondents might also be learning, I sought the benefits that other methodological perspectives might offer. I wanted a methodological additive that would philosophically mesh with Heideggerian phenomenology, but with a greater emphasis on the context of these women's lives and my perceived need to gather information about their lives from multiple sources. I turned to naturalistic inquiry.

Naturalistic inquiry has been used elsewhere in combination with other methodological and philosophical approaches. For example, Belk et al. (1988) used naturalistic inquiry combined with an ethnographic perspective, describing Buyer and Seller behaviour at a swap meet, a marketing gathering. Similarly, Thousand et al. (1999) used a Freirean-compatible naturalistic inquiry framework known as dialogic retrospection as a research process to elicit voice, with the voices of interviewees illustrating different themes (Thousand et al. 1999, 323). Several naturalistic inquiry studies have also focused on health-related concerns. For instance, Sullivan-Bolyai et al. (2003) used naturalistic inquiry to conduct qualitative interviews and analyse data from mothers who reported behaviours of constant vigilance to manage the health of their children with Type 1 Diabetes (Sullivan-Bolyai 2003, 21). Zambroski (2003, 32) used naturalistic inquiry to explore the experience of living each day with heart failure, deliberately using purposive sampling to select a diverse collection of participants who shared in common the experience of living with heart failure (Zambroski 2003, 33). Baird (2003) also followed this line, in her study of self-care in those with osteoarthritis. What is

clear is the diversity of research problems and perspectives that have been comfortably and successfully explored using naturalistic inquiry.

With naturalistic inquiry, I also considered my role as an “insider-outsider” researcher. I noted that Henderson et al.’s naturalistic inquiry of young children’s literacy also utilised both the insider-researcher and outsider-researcher perspectives to great effect (Henderson et al. 2002, 309). Naturalistic inquiry, like Heideggerian phenomenology, also recognizes the need for a window of meaning on lives where multiple realities can be revealed through thick description (Green 2002, 14), essential in this study. I was also reassured that naturalistic inquiry assumes that there is no single objective reality, but multiple realities of which the researcher must be aware – a vital contextual component of this research.

Many of the fundamental tenets of Heideggerian phenomenology and naturalistic inquiry overlapped in their philosophical orientations. I noted elements of naturalistic inquiry that I had previously worked with in phenomenological studies: the human being as research instrument; tacit knowledge; qualitative methods; purposive sampling; inductive data analysis; the case report; thick description, and idiographic interpretation being trenchant examples (Lincoln and Guba 1985; Green 2002, 8). Another fundamental assumption of naturalistic inquiry is that respondents are bound together by a complex web of unique interrelationships and experiences that result in mutual simultaneous shaping of their lives (Erlandson et al. 1993, 16). Certainly relationships played a key role in the lives of these women. It was recognized that complex and interwoven concepts, like relationships, necessitate a holistic approach to inquiry (Glesne and Peshkin 1992; cited in Harris et al. 2002), that both Heideggerian phenomenology and naturalistic inquiry offer.

In addition to these key areas of overlap, the focus on context in naturalistic inquiry is viewed as holding the key to all meaning (Lincoln and Guba 1985; Erlandson et al. 1993, 16; Green 2002, 5). Most naturalistic inquiries utilise a specific organization or project as the context for study and, while the context of this study was not a physical or social context that all respondents lived or worked in, the concurrent contextual dynamics that involved the personal, psychological, social, relational, financial, physical and emotional responses of respondents was vital. The contextual constant in the respondents’ lives was both

the need to manage their substantial caring responsibilities with the continual demands of full time work. It was the continual entanglement of their full-time work and caring responsibilities that presented constant dilemmas and challenges in all areas of their lives.

*1. Prospective perspective; clarification and data:*

The second stage interviews were designed to clarify or further explore issues raised in the Stage 1 interviews. Transcription and early analysis had been undertaken between interviews, and emergent themes were further explored and uncertainties remedied. For example, I returned to the second interview with Dolly, asking her more about her situation of “doing-it-all”. Dolly had told me in the first interview that she rarely had an unbroken night’s sleep because her daughter still has regular night seizures, or was wakeful and restless. Dolly reported still having to get up at night to attend to her child (as there was no-one else) while still having to go to work the next day. I explored her sense of feeling overwhelmed and having to “do-it-all”, asking her what she might do about this situation in the future:

**Researcher:** You also spoke last time about your concerns about feeling overwhelmed, that it’s “all you” in terms of coping with Margaret. You expressed concerns about not being able to continue, perhaps, doing it all in the future. What sort of things might help with this situation, for you?

**Dolly:** Well, probably at the time, I don’t know that I had the other carers in place. So I think having a bigger network, for me, is important ... I feel that it’s a bit bigger now, and it probably wouldn’t hurt to actually try to increase that again somehow, I don’t know. I think that’s an opportunity thing. I’ve got to go to mothers’ groups or school groups or something like that – which I haven’t actually got time to do – to sort of create those opportunities. My problem with some of those groups is that they usually work on a pay-back system – “I’ll look after yours and you look after mine.” I can’t promise to look after someone. So it’s going to be more that I can just add more people to my minding pile, if I need to (Dolly, #2, 15-16).

In this extract, we see the shift to the *prospective* perspective. While learning more about Dolly’s lived experience with “doing it all”, we also see further

evidence of her multiple lives, multiple roles and multiple identities. However, also presented are her changes in behaviour and thinking as a result of the research process and her reflections about getting assistance with caring for her child. “Local theory” was created here through the discussions between researcher and participant. The plan for action also must be created at the local level (Palshaugen 2004a, 189). Dolly demonstrated her plan for action in her conversation with me. She had acted upon her need to find carers and had thought through her options, given her particular contextual constraints. Other participants responded in similar fashion. For example, in Interview 1, Sandra had reported feeling very resentful of her partner, believing that her having to “do it all” had added immeasurably to the strain of an already difficult situation (Sandra, #1, 9). She had admitted that she was unhappy that her partner, Robert, was not able to provide more emotional support when it was needed (Sandra, #1, 9). Sandra also commented, on a number of occasions, about feeling overwhelmed, of being overtaken by all her responsibilities. During the second interview, however, Sandra spoke of her need in the future to “pass back” some of the burden of responsibility for family caring. Sandra also constructed her plan for action:

**Researcher:** If you had your time over, would you respond to the situation with Robert [Sandra’s partner] differently?

**Sandra:** Differently [nodding].

**Researcher:** Yes, what would you do?

**Sandra:** I wouldn’t let him -, I wouldn’t take on the carer role for him to the level that I’ve been the protector for him for such a long time. And I did it initially out of huge love and trying to make it better and help him, and all I did was really just give him more and more reason not to be involved.

**Researcher:** Allowed him to not take responsibility?

**Sandra:** Yes, yes. ... And I’ve often thought to myself that I’ve created a rod for myself, because I have; I’ve taken everything on (Sandra, #2, 7).

The concept of “local theory” was launched as a phenomenological concept, to express the experience that knowledge, to be actionable, had to be reconstructed in a local setting (Palshaugen 2004a, 184). Clearly, in both Sandra’s and



Dolly's accounts of "doing-it-all", learning was taking place, not just in terms of developing local theory, but via the demonstrated pragmatic outcomes in terms of actionable knowledge depicted as changes to their behaviour (Palshaugen 2004a, 184). This kind of change in interpretation of their own knowledge is one of the main vehicles to produce actionable knowledge at the local level (Palshaugen 2004a, 190). Other respondents also indicated such changes as a result of reflecting on their lives. For example, Polly started showing concern for herself by walking to lose weight and get fit, while Oitk (One Income Two Kids) made the necessary changes to her work schedule to continue her psychology degree, which she felt was a vital constituent in her life. The crucial issue here was not just the quality of the insights and knowledge gained, but the action plans that emanated from that knowledge. The question of what to do was accompanied by the no less crucial question of how to do it (Palshaugen 2004a, 190) – how to make the life changes required. Dolly confirmed her actionable knowledge outcome of putting herself "back on the list":

**Researcher:** If you had your time over, would you do anything differently?

**Dolly:** Absolutely. I'd put myself back on the list. Because I think, by not looking after myself, physically, emotionally, spiritually, I think that's brought a whole lot of the other things undone in my life. I think it's been a contributing factor to a whole bunch of stuff that I could have managed better; I could have managed my mother better, I could have managed my husband better. I would have felt a lot better. I wouldn't have put on five or six stone. I would have felt a lot more positive about who I was, and a bit more in control. So, yes, if I knew what I know now, I would definitely have done things differently (Dolly, #2, 8).

What is evident here is the meaningful connection between reflection and action by participants. The "agent" of this local theory was not the researcher, but the participants in the process. They were engaging in the process of bringing local theory into local and meaningful practice (Palshaugen 2004a, 186). The purpose of their change in thinking and action was an improvement or innovation; a new kind of action required by their circumstances. The plan was, thus, created by new ideas generated and by the construction of new

proposals for action (Palshaugen 2004a, 189). Action researchers confirm that the only meaningful way to theorise is through successive cycles of combined reflection and action, the action feeding back to revise the reflection in ongoing cycles (Greenwood 2002, 125). Participants were reflecting on their circumstances, behaviour, and feelings, and responding to that. As Greenwood (2002, 127) confirms, action research is not about imposing expert knowledge on stakeholders, but where knowledge, often very different, is shared between researcher and participants in a manner that can ameliorate problems. The vast difference between “telling” people theory, as opposed to involving people in its discussion and creation, was witnessed here. Transferring knowledge, which in practice means a local reconstruction of knowledge, took place via an encounter between researcher and respondent, with the most effective encounters being some kind of dialogue, as was the case here (Palshaugen 2004a, 187).

## *2. Responses to vignettes*

Participants in Stage 2 were also presented with case study vignettes that had been developed as a result of the data gathered from Stage 1. Vignettes centered around the difficulties these women had reported, such as: Not being able to apply for a particular job because of the responsibilities that caring for their child entailed; inadequate time and energy; ongoing loss and grief; fear surrounding the development of new (partner) relationships; support received or not received; childcare concerns; “family friendly” policies in workplaces; responses to emergencies concerning their child, especially while at work; disguising and covering child-related concerns in the work context; insufficient knowledge of support services and financial assistance; questions of disclosure related to their child, especially at work; and, coping strategies. The respondent’s experiences reported in Stage 1 provided direct input into the research process, as did my orientations, choices and perceptions in selecting incidents to adapt for vignettes. Texts that had resonated with me most strongly from Stage 1 were most influential. In total, fourteen fictional vignettes were developed, and six or seven of these were selected for presentation to each participant in Stage 2. Care was taken that vignettes based on a respondent’s own experiences were not re-

turned to them and attention was also directed to vignettes being allocated that might be most relevant to respondent's particular circumstances. It was intended that these vignettes would spark further knowledge generating dialogues between researcher and respondent. As it is legitimate for different interpretations of situations to exist (Palshaugen 2004a, 189), I was interested to see if these women would respond with similar interpretations to me. Vignettes ranged from a short paragraph, to longer scenarios involving several pages needing to be read, with questions at various points along the way.

I begin by sharing an example of data collected during Stage 1 which provided direct input into one of these vignettes. Cate worked full time, had a four year child with autism, a disabled adult brother living with her, a husband who didn't appear to work or assist with home duties in any meaningful way, and another two year old child to care for. She shared this compelling anecdote, which was preceded by her comments that she felt unable to leave her husband alone with her autistic son for any length of time.

**Cate:** It was a day when the kids were home because it was Christmas Eve. The kids were home, no day care. I had to work but I was going to come home early. I said, "I'm coming home early. You've got to watch the kids, but don't worry because I'll be home early." And so I went home, and it was about two in the afternoon, and his car was not there. And I went inside and guess who's there? The two kids – alone ... And I was, "What is going on?" They were just sitting in the living room, but you can't leave a two-year old and a four-year old home alone. So I started to hit the roof within myself, and then about forty minutes later he shows up – with alcohol. You know, he's got alcohol. He was already alcoholized up. He was already "shit-faced" [drunk] (Cate, #1, 21-22).

Thus, Vignette #10 was created, directly inspired by Cate's experience:

*You have had considerable difficulty finding someone to look after your child during school holidays, and to be there after school when the child arrives home, around 3 pm. However, you find this person in the local paper. They have references and appear knowledgeable (well, a bit) about your child's illness. They are confident with the child, and tell you they have worked as a nurse's aid at a hospital some years ago.*

*On this particular day, you arrive home from work early. You have just got a promotion and decided to give yourself a reward by taking the rest*

*of the afternoon off. You arrive home and find your child sitting in front of the television in a dirty nappy. This is not just any dirty nappy. It should have been changed many hours ago.*

*Where is your carer? Nowhere to be seen. You notice – for the first time since she started work – a dirty ashtray, full of cigarette butts. You recall asking her if she smoked when you interviewed her for the job, because you didn't want cigarette smoke around your child. She had said no.*

*About 20 minutes later, the carer arrives home, sees you and is very apologetic. She tells you that she just had to get some cigarettes down at the local shop and was only a few moments.*

*It is Friday, and next week is school holidays. What do you do? How do you feel? What are you most concerned about – now and in the future?*

Evalyn was one of the participants asked to respond to this vignette. Evalyn also worked full time, had a young son with severe epilepsy and significant intellectual disability, and another dependent child to care for. Unlike Cate, Evalyn reported a supportive partner relationship. However, she had also expressed to me her concerns and difficulties with finding suitable careers for her child:

**Evalyn:** Oh, this is a difficult one. I wouldn't be happy... I would not be happy.

**Researcher:** Which particular issues would make you unhappy?

**Evalyn:** The most serious issue is leaving my child alone. I can't really have a carer that smokes around my child, and I'm not really excited about it; I don't like it. But I feel that smoking is –, I'd rather have a caring carer than a non-smoking, non-caring carer. Smoking really wouldn't –, I don't like it but it's not something that I would sort of see as a big determinant in whether someone is a good carer or not. But a dirty nappy – okay. That's not my situation and obviously is a sign of neglect – but the really serious neglect was the fact that she left my child alone for who knows how long! And that's serious. That's not good enough. I could not, in good conscience, allow that carer to look after my child – absolutely not! That's just not acceptable, leaving my child alone. If it was leaving my child alone and going to bring the clothes in, okay, I could understand that, because it's just going out to get the clothes in. But leaving my child alone to go and buy cigarettes – which is, I don't know how far away –

that's *appalling* [incredulous]. Okay, it's extremely disruptive because next week it is school holidays, but I'm going to have to let this carer go. I'd feel absolutely appalled. Just devastated that I –, I'd be really upset about this thing. I'd ring the referees and tell them off. Concerned about now? Of course, I'd be very concerned about the future because it's not easy finding carers who are supposed to be experienced, but I'd just have to get around it and ring my mum up [laughter] (Evalyn, #2, 16-17).

Evalyn shares her feelings of grave concern – even fear – that a carer might leave her disabled son alone for any period of time. She also highlights the difficulty that many of the respondents had in getting quality carers for their child, especially at short notice. Notice also that it is Evalyn, not her partner, who would have to organize the new carer.

***Stage 3: Culminating group experience: Naturalistic inquiry; member checking; actionable knowledge and change***

The Culminating Group Experience was not run as a traditional focus group. Instead, the trustworthiness of the findings and interpretations made by the researcher were being checked, as was evidence of actionable knowledge as a result of the research process at the local level. Additionally, I informed respondents that the session would also be taped and transcribed, enabling me to utilise their feedback and commentary as further data. Many studies using naturalistic inquiry gather data from multiple sources for triangulation (Lincoln/Guba 1985; Erlandson et al. 1993, 31; Harris et al. 2002, 11). The best way to elicit the various and divergent constructions of reality that exist is to collect information about different events and relationships from different points of view (Erlandson et al. 1993, 31), which is what I sought to do. Similarly, Mason's naturalistic inquiry included two rounds of interviews (being pre-instructional and post-instructional interviews), group discussions and individually written outcomes (Mason 2001, 311-312).

Unfortunately, due to the overwhelming responsibilities respondents continued to shoulder, only two respondents were able to participate at the scheduled group session. However, the discussion still offered material evidence of actionable knowledge outcomes. Stage 3 commenced with a seminar-style presentation of my initial findings, to check for reasonable accuracy

and completeness. I also planned to ask respondents whether their participation had been a positive or negative experience, and whether it had resulted in any changes in their thinking, behaviour, or feelings since the study commenced. Again, learning and actionable knowledge outcomes were portrayed via respondents' comments about their participation in the project, their responses to data presented, and the subsequent discussion. This search for common ground (Palshaugen 2004a, 189) found Wendy sharing her reflections on the theme of "doing-it-all". Wendy was clearly agreeing with my researcher developed interpretations, but also sought to add her own local interpretation of the "invisibility" of doing it all:

**Wendy:** I've just been thinking, one of the things that struck me is it's like housework. It's invisible. And the theme of invisibility. And then, just then, if you go: women's housework, women's mothering and caring, and *then* the carer of the disabled or ill. It's the triple-load; it's not the double workload, it's the triple-load. You have the triple bottom line in business; you have the triple bottom load. It's not a double whammy; it's an extra one (Wendy, CGE, 3).

Importantly, though, we also see evidence of the change associated with that learning for Wendy. She specifically pointed out that she had begun to act upon her own needs since participating in the project; she had created her action plan in response to her local knowledge and was now describing her practical outcome of that. This wasn't just a discussion about local theory that had developed, but had become a practical discourse – the kind of discourse oriented towards *doing* something (Palshaugen 2004a, 194; emphasis in original). Wendy shared how she had been able to "hand over" a small part of the responsibilities relating to her child's care to her daughter's father. This, she explained, involved recognition by him of the mental, as well as physical, activities involved. It also meant for her, saving half a day a month of her precious time and energy:

**Wendy:** We have to do a monthly trip down to Sydney to pick up medication. And I've now got to the point of having been able to train my kid's father to go and do that. And he's moved from going and collecting it when we ring up and check it is in the pharmacy and all of that. He's now moved to: "What are you going to do when you're away and you need the second one? You'd better ring the doctor and get a double dose." And I'm handing it back. It's like: "Talk to your dad and make sure that he has

enough scripts.” So I’m managing it more and more remotely, so that now not only does he pay the monthly prescription cost, but he also goes and picks it up – anticipates it. He throws his little “wobbles” when it’s not there, and rings me up in meetings and tells me, “What am I going to do about it?” And I just say, “Sorry, I’m in a meeting. Bye, bye!” [Laughter] You know, it’s that invisible “packing the bag” [referring to Dolly’s earlier comments from Stage 1] and all of that.

**Researcher:** But you’ve had to manage it back to your partner too; it hasn’t just happened. You’ve had to figure out, “How am I going to do this?” And you’ve got your daughter to do this.

**Wendy:** That’s right. And that’s only a tiny little bit.

**Researcher:** *I know.* That’s just one little bit.

**Wendy:** That’s one monthly -, that’s four hours a month. That’s half a day a month, but that’s quite considerable for me (Wendy, CGE, 15)

Both respondents also reported that they felt better knowing that they were not alone in their circumstances. Wendy suggested that, “some people have it much worse” (CGE, #3, 1). Evalyn agreed, adding:

**Evalyn:** Yes. And it makes you realise that you’re not alone, which is really important. Because I guess, amongst your family and friends, you are a minority. And so you don’t get to see and hear of other people who have the same kind of experiences. So it’s really wonderful to get that (Evalyn, CGE, 1).

This sense of not feeling quite so alone in their struggle seemed to be a comforting factor for them both. Evalyn also demonstrated her new learning about mothers taking on the majority of the work, of “doing-it-all”. She reported being surprised that she was one of the few respondents in a supportive relationship. However, she also recognised, for the first time, that her partner was “supplementing” her efforts, rather than sharing them equally:

**Evalyn:** Yes. I totally agree with your finding, at the end, that mothers do tend to have the primary caregiving role and the father is seen as a supplement, almost like a supplementary kind of caregiver. And I was really surprised at how many negative cases you found where the father was almost detrimental to the caregiving process, and wasn’t really supportive or anything. I guess I was very lucky in that respect, because my husband has

been very supportive and caring. And I know a family where it has split them up. So I guess I'm lucky in that respect. But I was surprised that it was almost like a minority (Evalyn, CGE, 2).

Evalyn was learning from the dialogue insights into her partner relationship. She also expressed the positive and practical outcome of how finding that she was not alone in her experiences was a positive outcome in itself. While this new knowledge may or may not result in behavioural changes for Evalyn – *actionable* knowledge in the pragmatic, physical sense – it was still learning that resulted in the very real practical outcome of making her feel more content, more comfortable and comforted. She also felt less alone than she did before participating in the study, and appreciative of her partner's contributions and support. Such an outcome was very valuable for the recipient. Evalyn's concluding commentary shared her ultimately positive, although mixed, experience with participating in the study. She shared her feelings of ambivalence experienced during my presentation of the emergent themes and stories from other women:

**Evalyn:** I felt when we were actually reading, telling us about your experience in your studies, it was kind of really sad. I felt really sad. And I, you know, I felt like crying a couple of times at how sad some of these stories were. But right now, talking here right now, I feel quite positive. You know, it's how you deal with the situation (Evalyn, CGE, 6-7).

The knowledge-generating dialogue that was created in the Culminating Group Experience resulted in Evalyn ultimately reporting feeling very positive. For her, the improvement and innovation in her life lay with acknowledging the plight of others, and knowing that she was dealing effectively and positively with what life had handed her. The creation of positive feelings, including increased self-efficacy, was a worthy actionable knowledge outcome indeed.

### **Towards further actionable knowledge**

It is hoped that this paper has succeeded in achieving what it set out to do. I wanted to share a useful research design with others, because I felt it enabled rich data to shed light on the plight of a group largely ignored in the past. The



research design was shaped by the philosophical and methodological contributions of several overlapping but complementary research approaches: action research, usefully incorporating the philosophical perspectives of Heideggerian phenomenology and naturalistic inquiry. I think that their combination has been a fruitful one, producing rich data informed by respondents' subjective experiences, reflections and learning. I also believe that actionable knowledge, especially at the local level, in the lives of the respondents who participated in this study, has been demonstrated. The dialogues we had have prompted their reflection and learning, as well as the development of 'local theory' as an important foundation for action (Palshaugen 2004a, 184). However, and importantly, the respondents have also demonstrated changes in their knowledge of their own situations, enabling them to create action plans that resulted in pragmatic, meaningful action to improve their lives.

The local knowledge and researcher interpretations created from this study have also been utilized outside the situation to further improve the human condition, but on a much larger scale. The exploratory work undertaken in the study reported here served to support a successful application for an Australian Research Council Linkage Grant application. Hence, useable knowledge from this exploratory study will now be used to address the specifics of this practical problem on a wider scale. The grant application details the action plan, which specified the specific human problems which needed to be addressed, and included specific details of what to do and how to do it. So, from local theory we have local actionable knowledge applied in a very pragmatic way on a larger scale. In this case, this larger research project, now underway, is planned to uncover more detailed information, quantitative and qualitative, about the support needs of full time workers caring for a child with chronic illness across Australia. Greenwood (2002) confirms that action research need not just include qualitative studies. Specifically, the outcomes of this larger study will include: enhanced understanding of the support needs of full time workers who care for a child with chronic illness; qualitative and quantitative data to inform policy makers, health care providers, employers, educators, and health care professionals to provide more proactive, responsive and responsible social support and information services; and, a validated, sensitive questionnaire that will provide empirical data about the support

needs of people who work full time and care for a child with chronic illness. Hence, the impetus and action for social change continues.

I also draw attention to the challenges involved in attempting to make social change, especially on a large scale. I point to Greenwood's (2002, 129) concerns that action researchers may feel oppressed by both the academy and by public sector agencies dominated by more conventional social research agendas and power orientations. In Australia, as in many other countries, the transition from encounters and dialogues at a local level between researcher and participant, to actionable knowledge at a national level in the form of policy development, support services, information provision and educative assistance directed in the right areas, is an extremely competitive one, and a path not paved with many methodological sensitivities. Certainly, in Australia, one is less likely to achieve funding for projects that do not profess to deliver "concrete", "scientific" and "quantifiable" outcomes. Proposed projects that exude the vagaries of an evolving, fluid, and unstructured project are hard to defend. However, in order to make significant social changes, such financial and institutional backing is often imperative. The balancing act that inevitably follows is not easy.

However, I share Gustavsen's (2004, 163) sentiments on the worthwhile nature of longer-term projects, especially in terms of their capacity to expand into different discourses and lines of discovery. The likelihood of social change might be enhanced with some preparedness of action researchers to deliberately include the gathering of "scientific" and "objective" data – data that is routinely insisted upon by decision makers (and might often be outside the action research arena) – as part of *their means to effect change*. As Greenwood (2002, 131) insists, conducting good research means developing habits of counterintuitive thinking, linking findings and processes located in other cases, and attempting to subject our interpretations to outside critique. In taking this project forward in a more positivist direction is, for me, taking up such a challenge.

Action research must address social problems, which are inevitably driven by external funding sources and professional bodies (Greenwood 2004, 119). While agreeing with Palshaugen's (2004b) sentiments that valid knowledge does not only come from one theoretical perspective – the "scientific" or

positivist one – in order to bring to the surface issues of importance, one might consider being prepared to adhere to the “rules of the game” as defined by those with such influence, to achieve one’s ultimate objective. If, as Palshaugen (2004b) and Gustavsen (2004) argue, the current pool of knowledge is *perceived by the majority* to emanate from one “true” source (i.e. positivist science) then, undertaking research in accordance with those “rules” is an intelligent choice for an action researcher who wants their work and the outcomes of it to get the hearing it deserves. While I have also been responsible for attacks on positivism (also articulated by Greenwood 2004, 118), I acknowledge the importance of making interesting to those in power those issues that interest me, that require action and change. And so I proceed with that in mind.

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